# Washington State
# Birth Defects Surveillance System

## Status Report 1995-2004

Washington State Department of Health

**Acknowledgements**

We are grateful to the facilities in Washington State that are sending data to the BDSS, and to the staff at those facilities who continue to support our efforts; and to the facilities where BDSS staff have been welcomed to carry out quality review studies.


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## Table of Contents

**Background and History**

In 1984 state legislation was enacted to make sentinel birth defects reportable, to create a birth defects registry and to mandate reporting of children born with birth defects. Subsequently, the Washington State Birth Defects Registry (BDR) was established 1986.

From 1986 through 1992, the Washington Department of Health (DOH) maintained an active birth defects registry with support from a Centers for Disease Control and Prevention (CDC) cooperative agreement. The system combined passive reporting from hospitals with active hospital based case record review and abstraction by BDR staff. During the early 1990s, the BDR was redesigned to accommodate funding decreases and surveillance methodology was modified to a passive surveillance system in 1992. Staffing decreases and competing priorities within the Department of Health led to declines in reporting over time.

In 1997, efforts were undertaken to evaluate the passive surveillance system, identify data needs, improve reporting, and introduce efficiencies to make the system sustainable given limited long-term funding. Additional funding for surveillance improvements was obtained from the CDC in 2000. As part of DOH efforts to improve all notifiable condition reporting, the Washington Administrative Code was revised and nine birth defects were selected for inclusion to the notifiable conditions reporting requirements. A broad-based stakeholder advisory board determined that the following conditions be included:

- Neural tube defects
- Oral clefts
- Hypospadias and Epispadias
- Limb reduction defects
- Abdominal wall defects
- Down syndrome
- Fetal Alcohol Syndrome
- Autism
- Cerebral palsy

## Introduction

Birth defects are inborn syndromes, disorders and malformations that occur before birth. They can affect the organs, senses, limbs, and physical and mental development. They also cause pregnancy loss through miscarriage and stillbirth. Some conditions are recognized prior to or at birth, others become apparent later in life.

In the United States, birth defects are the leading cause of infant mortality and years of potential life lost, as well as contributing substantially to childhood morbidity/long-term disability.[1, 2]

Education of health professionals and the public about factors that may be related to birth defects is crucial for prevention. The U.S. Public Health Service recommends that all women who could possibly become pregnant take 400 micrograms (or 0.4mg) of folic acid every day. Fifty to seventy percent of many serious birth defects could be prevented if this recommendation was adhered to[5]. Over 50% of births in Washington are unintended, so it is important to promote daily consumption of folic acid to all women of childbearing age. Early identification of birth defects promotes care coordination and secondary prevention activities to improve the quality of life for the child and the family.

The purpose of this report is to describe the status of the Washington State Birth Defects Surveillance System, to compare preliminary data from the system and to identify necessary steps to improve that system.

## Methods of Surveillance

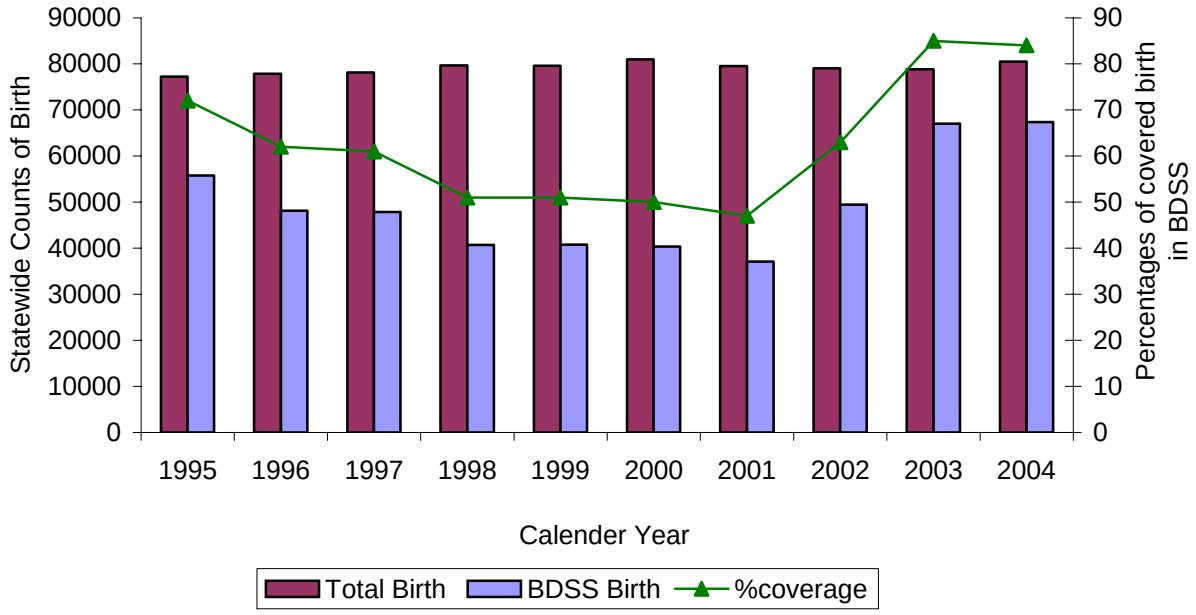
Currently Washington State Birth Defects Surveillance System (BDSS) relies on hospitals to regularly report their data on children with the following conditions: neural tube defects, cleft lip/palate, hypospadias/epispadias, abdominal wall defects, limb reduction defects and Down Syndrome. Currently, birth and death certificate are not allowed to be used for surveillance of identifiable cases. Hospitals must report cases of birth defects separately to the BDSS. When the report is received at the BDSS office, the data are processed and entered in an electronic database. This data is augmented with cases served by the Children with Special

Health Care Needs (CSHCN) programs located throughout the state. See Appendix 1 ICD-9-CM codes for case definitions.

Autism, Fetal Alcohol Syndrome (FAS), and cerebral palsy are included in the list of notifiable conditions; reporting these has been delayed as they are conditions not identified in the hospital setting. Plans are being developed to establish a case definition and reporting protocols.

The accuracy of the surveillance prevalence estimates depends on the number of facilities reporting data regularly. The following graph shows reporting compliance during the 1995 – 2004 time period. This report tracking shows the decrease and then gradual increase of compliance by hospitals.

Figure 1. Statewide Counts of Births in Washington State (Total Births) and Counts and Coverage Percentages of Births in Washington State BDSS, 1995 through 2004




Since 2000, the BDSS activities have focused on improving passive reporting for these conditions. This work includes actively facilitating hospital reporting, integrating available sources of data, encouraging other health care providers to report and designing and building a web-based reporting system.

Since 2003, approximately seventy-five percent of the birth and pediatric hospitals have been reporting. This includes 15 of the 16 sentinel facilities (pediatric hospitals and birth

hospitals with 1,500 deliveries or more annually). Eighty-four percent of births that occur in the State are delivered at a birth facility that reports to the BDSS system.

**Information from Reported Data**

The data presented in this report covers from 1995 through 2004 with a focus on 2003 and 2004, the years with the highest reporting. Rates were calculated using the number of cases reported for the selected birth defect conditions from live births as a numerator and the total births reporting to Washington residents occurring at a Washington facility as a denominator. The estimates are per 10,000 births.

When the prevalence rates were calculated for Washington State, they only appear comparable to the national estimates for cleft lip/cleft palate, abdominal wall defects and Down Syndrome (Table 1). The use of a passive surveillance system, the lack of data from the non-reporting facilities and the non-reporting of fetal deaths from most facilities may have skewed the prevalence estimates, not reflecting the "true" magnitude of birth defects in Washington State. The figures reported should be used with caution to avoid unintended inferences.

Table 1. Prevalence Estimates of the Listed Birth Defect Conditions.

| | National Estimated Prevalence Rates (1999-2001)[6] | Estimated number of Infants with Reportable Conditions born in Washington State in 2003-2004 based on National Rates | Washington State Birth Defects Surveillance System Prevalence Rates (2003-2004) | Average Annual Number of infants with Reportable Conditions in Washington State (2003-2004) |
|---|---|---|---|---|
| Anencephalus | 2.5 | 19 - 22 | 0.8 | 6 |
| Spina Bifida | 3.7 | 27 - 32 | 2.1 | 17 |
| Cleft lip/cleft palate | 16.9 | 128 - 143 | 17.6 | 140 |
| Hypospadias / Epispadias | ------ | ---- | 21.3 | 169 |
| Limb reduction defects | 5.7 | 43 - 48 | 2.5 | 20 |
| Abdominal wall defects | 5.8 | 44 - 49 | 5.4 | 43 |
| Down Syndrome | 12.8 | 99 - 106 | 12.1 | 97 |

Prevalence estimates (per 10,000 births)

**Data Validation Studies**

To use birth defects data for planning and research, it is important to know how complete and reliable the data are. To examine the quality of birth defects data collection in Washington State's BDSS, a medical records re-abstraction survey was conducted by BDSS staff in two major hospitals in the Puget Sound area in 2002 to determine the accuracy of reported data.[7,8] Using the BDSS database, discharge dates from January 1, 1998, through December 31, 1999, were selected and resulted in 130 cases from these two hospitals. Re-abstracted information was recoded (ICD-9-CM) and then matched to the codes originally submitted. The results for neural tube defects, cleft lip/palate, hypospadias/epispadias and upper and lower limb reduction defects matched at the rate of 100% for the first three digits. However, as the level of diagnostic specificity increased, the matching decreased.

These findings are encouraging given the inherent problems with passive reporting, such as dependence on complete records, systematic processes for reporting and variations in abstracting and coding protocols and coding software. Differences could also be attributable in part to routine variation among medical record coders.

In addition to comparing reported cases' data with re-abstracted data, it is also important to determine whether all cases diagnosed with congenital abnormalities in a facility are reported to BDSS. One option includes review of medical records of children reported and review of hospital unit/department logs (surgery, lab, delivery, newborn nursery, etc), for additional cases during the same time period. Such a study of case-finding completeness was undertaken in 2003, looking at discharges for a two year period at two tertiary care centers. Some discrepancies were found between the number of cases reported from the hospitals' Discharge Index and careful review of other internal logs. However, the differences were fairly small.

**Quality Control/Quality Assurance**

In addition to re-abstracting and to searching unit/department logs, another option is to conduct a review of all medical records and hospital unit/department logs (surgery, lab, delivery, newborn nursery, etc) for children under age one, during a specified timeframe

without regard to any specific diagnoses. A study of this type is both time and labor intensive, but yields excellent comparative data[9].

**Recent Accomplishments**

The Children with Special Health Care Needs (CSHCN) Program in the Office Maternal and Child Health (OMCH) collaborates with BDSS to improve the connection of surveillance and services. In 2004, a Birth Defects Toolkit for health professionals was developed through a contract with the Center for Children with Special Needs at CHRMC. This toolkit incorporates information resources for public health professionals and families to help them understand birth defects, beginning with the notifiable conditions. The toolkit has been disseminated to Maternal & Child Health public health nurses who work with families in communities.

In an effort to advance surveillance of autism, FAS and cerebral palsy, a survey of other states' surveillance systems was completed during the summer of 2005. This survey was conducted by an MPH student from the University of Washington. In addition to collecting state information, the student interviewed recognized experts in Washington State for those three conditions to understand their perspectives and to gather their recommendations on what effective surveillance practices would include. That information is being considered as we proceed to develop plans to collect information about these conditions.

Recognizing the growing numbers of individuals diagnosed with autism, in the spring of 2005, the Washington State Legislature passed a bill pertaining to the creation of an Autism Taskforce which will investigate the multiple aspects of autism and prepare a report to the Legislature. The Taskforce is composed of medical and education experts, families, policy makers and public health, and includes a representative from DOH. The CSHCN Program in the Department of Health staff the Taskforce. MCH Assessment also supports the work of the Taskforce by providing national prevalence data, trends and review of the scientific literature. This attention should further support efforts in surveillance.

**Future Activities**

The intent of surveillance in Washington State is to provide information to policy makers so that thoughtful planning for the state's residents takes place; and to service providers so that early intervention is a reality for each child diagnosed with one of these conditions. Surveillance information can also inform prevention planning. The following activities will lead to realizing these goals:

- Increase the percentage of reporting facilities to 95% and of sentinel facilities to 100%;
- Review data and produce reports on a regular basis;
- Develop relationships with providers serving children with Autism, FAS and Cerebral Palsy in order to facilitate surveillance;
- Develop and disseminate surveillance protocol to providers for autism, FAS and cerebral palsy;
- Consolidate a core set of materials to add to the Birth Defects toolkits on the topics of autism, fetal alcohol syndrome and cerebral palsy;
- Develop a quality assurance plan to carry out further quality studies based on agreed upon study protocol(s) to improve data reported; and
- Promote electronic reporting to enhance efficiencies and save time for reporters.
- Improve reporting of birth defects occurring in fetal deaths

## References


1. Lynberg MC, Edmonds LD. State Use of Birth defects Surveillance. From Data to Action: CDCs Public Health surveillance for women, Infants and Children. Wilcox LS, Marks JS, eds. US Dept of Health and Human Services, 1994.

2. PW Yoon, et al. The national Birth Defects Prevention Study. Public Health Reports, 2001; suppl(1)Vol.116:32-40.

3. Joann Petrini, Karla Damus, Rebecca Russell, Karalee Poschman, Michael J. Davioff, and Donald. Contribution of Birth Defects to Infant Mortality in the United States. Teratology 2002; 66:S3-S6.

4. United States Department of Health and Human Services. 1990. Healthy People 2000: National Health Promotion and Disease Prevention Objectives. Washington, DC.

5. CDC. Spina Bifida and Anencephaly Before and After Folic Acid Mandate---United States, 1995-1996 and 1999-2000. MMWR. May 2004/53(17);362-365.

6. CDC. Improved National Prevalence Estimates for 18 Selected Major Birth Defects---United States, 1999—2001. MMWR Jan 2006/54(51&52); 1301-1305.

7. CDC. Updated Guidelines for Evaluating Public Health Surveillance System: Recommendations from the Guideline Work Group. MMWR July,2002/50(RR13);1-35.

8. Michele C. Lynberg, Gilberto F. Chavez, Joseph Mulinare. Congenital malformations Evaluation of Birth Defects Monitoring Program, 1982-85SurveillanceTeratology 1993; 48(6): 650 - 657.

9. M Kilkenny, M Riley and J Lumley. Follow-up validation study of the Victorian Congenital Malformation Register. J. Peditr. Child Health 1995; 31:323-32

# Appendices

## Appendix 1: Case Definition

| Disease Condition | ICD-9-CM Codes* |
|---|---|
| Anencephaly | 740.0, 740.1 |
| Spina Bifida | 741.0-741.01, 741.9–741.93 |
| Cleft Lip with or without Cleft Palate | 749.1-749.14,749.2749.25 |
| Cleft Palate | 749.0-749.04 |
| Hypospadias/Epispadias | 752.60-752.62 |
| Limb reduction defects | 755.20-755.29, 755.58, 755.30-755.39, 755.67 |
| Gastroschisis | 756.79 |
| Omphalocele | 756.79 |
| Down Syndrome | 758 |

## Appendix 2: More Information about the Individual Notifiable Birth Defects

**Rates for this section were calculated using the cases occurring in live births to Washington residents actually reported to the Birth Defects Surveillance System, divided by the number of births occurring in the state to Washington residents.**

### Neural Tube Defects

A neural tube defect is an abnormality resulting from failure of the neural tube to close in the first month of pregnancy. The major conditions are anencephalus and spina bifida. Anencephalus is a congenital absence of the skull, with cerebral hemispheres completely missing or reduced to small masses attached to the base of the skull. Anencephalus is not compatible with life. Spina bifida results from failure of the spinal neural tube to close. The spinal cord and/or meninges may or may not protrude. This usually results in damage to the spinal cord with paralysis of the involved limbs and organs which are controlled through nerves in the spinal column.

**Anencephaly** **Spina bifida**

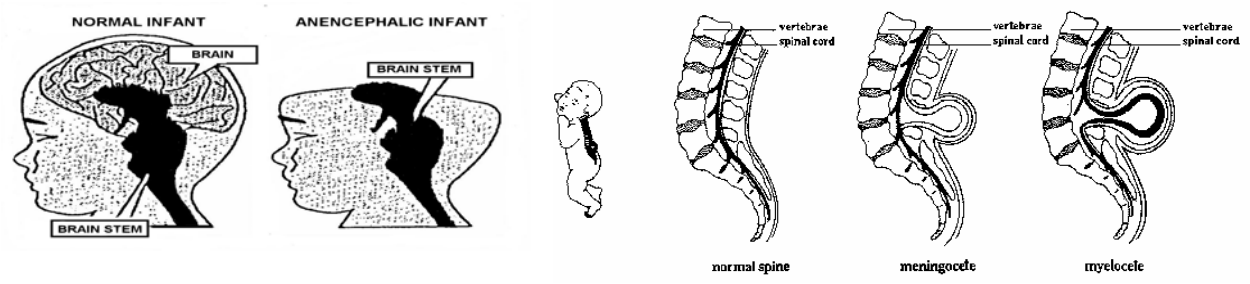



*Image Source*: http://www.anencephalie-info.org/images/med_sketch *Image Source*: http://www.babybag.com/articles/wh-folic.htm

Rates* of Anencephalus and Spina Bifida Per 10,000 births in Washington State 2003 through 2004.

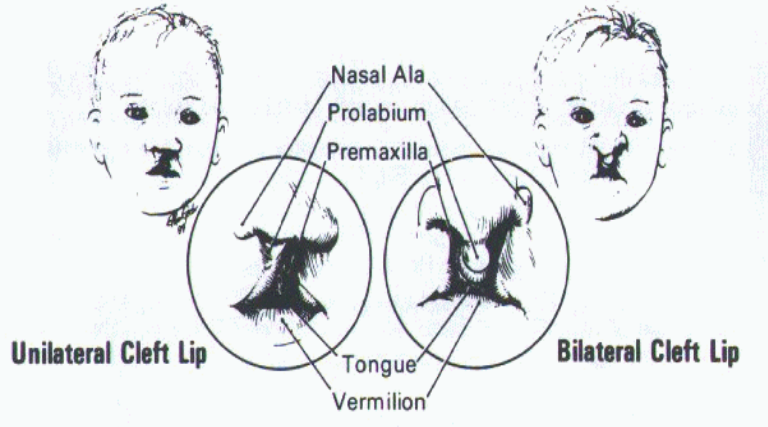
| | 2003 | 2004 | Avg |
|---|---|---|---|
| Anencephalus | 0.9 | 0.6 | 0.8 |
| Spina bifida | 2.8 | 1.4 | 2.1 |

* *Data from BDSS, 2003-2004*

## Oral-facial Abnormalities

The most common oral-facial abnormalities are cleft lip and cleft palate. Cleft lip is the failure of the fetal components of the lip to fuse or join, forming a groove or fissure in the lip. Cleft palate is the failure of the palate to fuse properly, forming a grooved depression or fissure in the roof of the mouth. The fissure can extend into the hard and soft palate and into the nasal cavities. Infants can have either or both conditions.

**Cleft Lip**




**Cleft Palate**

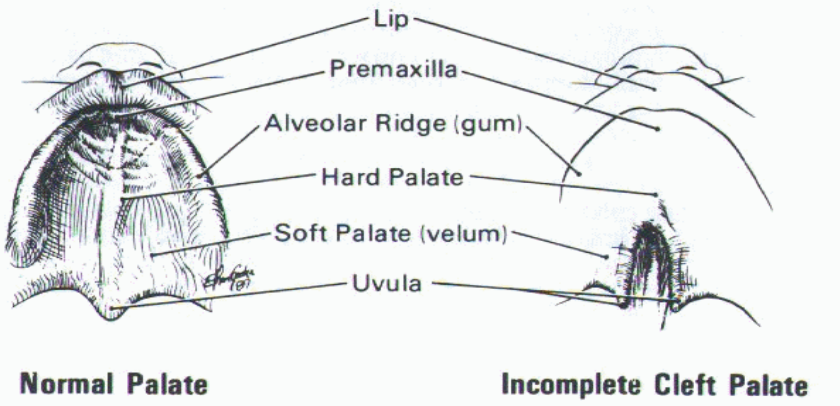



*Image Source:* http://www.cleftline.org/aboutclp/cleft_lip.htm

Rates* of Oral -facial Abnormalities per 10,000 Births in Washington State 2003 through 2004.

| | 2003 | 2004 | Avg |
|---|---|---|---|
| Cleft lip/ palate | 16.2 | 19.0 | 17.6 |

** Data from BDSS, 2003-2004*

## Hypospadias/Epispadias

Examples of male genital abnormality include hypospadias and epispadias. Hypospadias is a congenital defect in which the urinary meatus (urinary outlet) is on the underside of the penis or on the perineum (area between the genitals and the anus). The urinary sphincters are not defective so incontinence does not occur. The corresponding defect in females is rare.

Epispadias is a congenital defect in which the urinary meatus (urinary outlet) opens above (dorsal to) the normal position. The urinary sphincters are defective, so incontinence does occur. The corresponding defect in females is rare.

Rates* of Hypospadias/Epispadias per 10,000 Births in Washington State
2003 through 2004.

| | 2003 | 2004 | Avg |
|---|---|---|---|
| Hypospadias/Epispadias | 24.7 | 17.8 | 21.3 |

** Data from BDSS, 2002-2004*

## Limb Reduction Defects

Reduction defects of the upper and lower limbs refer to the congenital absence of a portion of the upper and/or lower limbs. There are two general types of defects, transverse and longitudinal. Transverse defects appear like amputations, or like missing segments of the limb. Longitudinal defects are for example, a missing radius and thumb or a missing tibia and a great toe.

### Limb reduction defects

*Image Source*: http://www.cbdmp.org/pdf/mvsheartslimbs.pdf

Rates* of Limb Reduction Defects per 10,000 Births in Washington State
2003 through 2004.

| | 2003 | 2004 | Avg |
|---|---|---|---|
| Limb reduction defects | 2.3 | 2.6 | 2.5 |

* *Data from BDSS, 2003-2004*

## Abdominal Wall Defects

Abdominal wall defects include mainly gastroschisis and omphalocele. Omphalocele, is the protrusion of an organ into the umbilicus. Gastroschisis is a congenital opening of the abdominal wall with protrusion of the intestine. The cause of abdominal wall defects remains unclear. Abdominal wall defects are effectively treated with surgical repair.

### Omphalocele/Gastroschisis

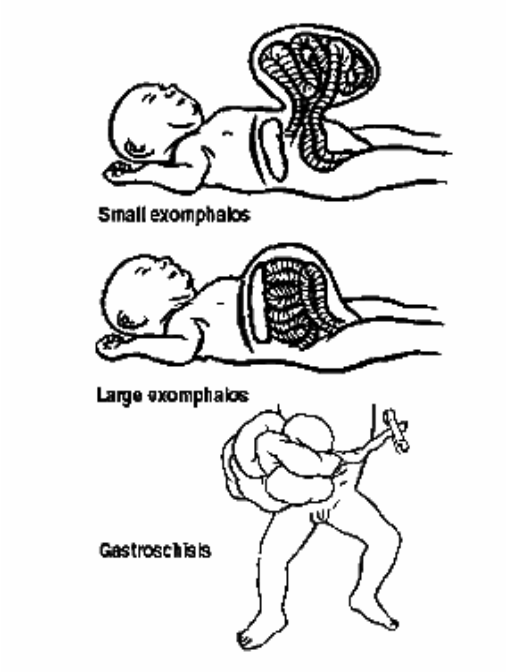



*Image Source:* http://www.ich.ucl.ac.uk/factsheets/diseases_conditions/abdominal_wall_defect

Rates* of Abdominal Wall Defects per 10,000 Births Washington State 2003 through 2004.

| | 2003 | 2004 | Avg |
|---|---|---|---|
| Abdominal wall defects | 4.4 | 6.4 | 5.4 |

* *Data from BDSS, 2003-2004*

**Down Syndrome (Trisomy 21)**

An extra copy of chromosome 21 characterizes this chromosomal abnormality. In rare cases, this syndrome is caused by translocation. The extra copy can be free lying, or can be attached to some other chromosome, most frequently chromosome number 14. Down Syndrome can occur in mosaic, so that there is a population of normal cells and a population of trisomy 21 cells. Moderate to severe mental retardation, sloping forehead, small ear canals, flat-bridged nose and short fingers and toes characterize Down Syndrome. Some children may have congenital heart defects, and/or duodenal atresia. Children with Down Syndrome are at increased risk for developing leukemia.

Rates of Down Syndrome per 10,000 Births in Washington State
2003 through 2004.

| | 2003 | 2004 | Avg |
|---|---|---|---|
| Down Syndrome | 11.9 | 12.4 | 12.1 |

* *Data from BDSS, 2003-2004*

**Fetal Alcohol Syndrome, Autism and Cerebral Palsy**

As mentioned earlier in this report, the collection of data for these three conditions has been delayed and current summary data from the BDSS is not available. The BDSS is working with research groups, providers and educational systems to begin data collection on these conditions within available resources.

Fetal alcohol syndrome (FAS) is a constellation of abnormalities including characteristic abnormal facial features, growth retardation, and problems of behavior and cognition in children born to mothers who drank alcohol during pregnancy.

Autism is a type of pervasive developmental disorder. It interferes with a person's ability to communicate with and relate to others. Autism is a lifelong condition that results in some degree of social isolation. Autism affects how a person perceives and processes sensory information. Signs of autism usually develop before a child is 3 years old, although the condition is frequently not diagnosed until later. Typically, parents first become concerned when they notice their toddler does not respond or interact like other children of the same age. Toddlers with autism do not usually babble or talk normally, and may seem to have hearing problems.

Cerebral palsy is a medical condition caused by a permanent brain injury that occurs before, during, or shortly after birth. The effect of cerebral palsy (CP) is characterized by lack of muscle control and body movement. While it is not a progressive disease of the brain, the effects of cerebral palsy may change gradually over the years. The cause of cerebral palsy has not been definitively identified, but it has been linked to the health history of both the mother and child, as well as to accidents that result in brain damage. The CP diagnosis is usually made shortly after birth, but may show up later in childhood.

## Appendix 3: Rates of Notifiable Birth Defects 2000 – 2004

Although current policy does not allow identifiable information from birth and fetal death certificates to be added to the birth defects registry, non-identifiable information was available to compare overall rates. The following tables compare cases reported to the BDSS (Table 1) to those included in the birth certificate only or either the birth or fetal death certificate (Tables 2 and 3). There are two factors to note. First, in comparing tables 1 and 3, note that the number of cases reported to the BDSS is generally significantly higher that identified on the birth certificate. This discrepancy mirrors national studies where birth certificates are a valuable source for birth defect case ascertainment. However, it cannot be relied on exclusively. Where the birth certificate identifies more cases of Anencephalus than the BDSS, may be a result of incomplete participation by hospitals. Secondly, in comparing tables 2 and 3, note that the rate is of birth defects that occur in fetal deaths and would not be accounted for in the BDSS using live births only.

Table 1: Notifiable Birth Defects as reported to Washington State Birth Defects Surveillance System

| | 2000 | | | 2001 | | | 2002 | | | 2003 | | | 2004 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] |
| **Anencephalus** | **2** | **79,415** | **0.3** | **4** | **78,021** | **0.5** | **2** | **77,471** | **0.3** | **7** | **78,858** | **0.9** | **5** | **80,150** | **0.6** |
| **Spina bifida** | **19** | **79,415** | **2.4** | **20** | **78,021** | **2.6** | **29** | **77,471** | **3.7** | **22** | **78,858** | **2.8** | **11** | **80,150** | **1.4** |
| **Cleft lip and or cleft palate** | **118** | **79,415** | **14.9** | **126** | **78,021** | **16.1** | **134** | **77,471** | **17.3** | **128** | **78,858** | **16.2** | **152** | **80,150** | **19.0** |
| **Hypospadias/Epispadias** | **111** | **79,415** | **14.0** | **149** | **78,021** | **19.1** | **195** | **77,471** | **25.2** | **195** | **78,858** | **24.7** | **143** | **80,150** | **17.8** |
| **Limb reduction defects** | **19** | **79,415** | **2.4** | **19** | **78,021** | **2.4** | **22** | **77,471** | **2.8** | **18** | **78,858** | **2.3** | **21** | **80,150** | **2.6** |
| **Abdominal wall defects** | **62** | **79,415** | **7.8** | **48** | **78,021** | **6.2** | **43** | **77,471** | **5.6** | **35** | **78,858** | **4.4** | **51** | **80,150** | **6.4** |
| **Down syndrome** | **68** | **79,415** | **8.6** | **83** | **78,021** | **10.6** | **105** | **77,471** | **13.6** | **94** | **78,858** | **11.9** | **99** | **80,150** | **12.4** |

* Rates per 10,000 births for the selected abnormalities 2000 - 2004

Table 2: Notifiable Birth Defects as reported on Birth and Fetal Death Certificates

| | 2000 | | | 2001 | | | 2002 | | | 2003 | | | 2004 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] |
| **Anencephalus** | **11** | **79844** | **1.4** | **10** | **78439** | **1.3** | **12** | **77905** | **1.5** | **18** | **79346** | **2.3** | **16** | **80,575** | **2.0** |
| **Spina bifida** | **9** | **79844** | **1.1** | **10** | **78439** | **1.3** | **11** | **77905** | **1.4** | **17** | **79346** | **2.1** | **14** | **80,575** | **1.7** |
| **Cleft lip and or cleft palate** | **87** | **79844** | **10.9** | **97** | **78439** | **12.4** | **93** | **77905** | **11.9** | **80** | **79346** | **10.1** | **90** | **80,575** | **11.2** |
| **Abdominal wall defects** | **36** | **79844** | **4.5** | **45** | **78439** | **5.7** | **38** | **77905** | **4.9** | **72** | **79346** | **9.1** | **28** | **80,575** | **3.5** |
| **Down syndrome** | **52** | **79844** | **6.5** | **55** | **78439** | **7.0** | **56** | **77905** | **7.2** | **44** | **79346** | **5.5** | **63** | **80,575** | **7.8** |

*Rates per 10,000 births for selected abnormalities 2000 - 2004

Table 3: Notifiable Birth Defects as reported on Birth Certificate

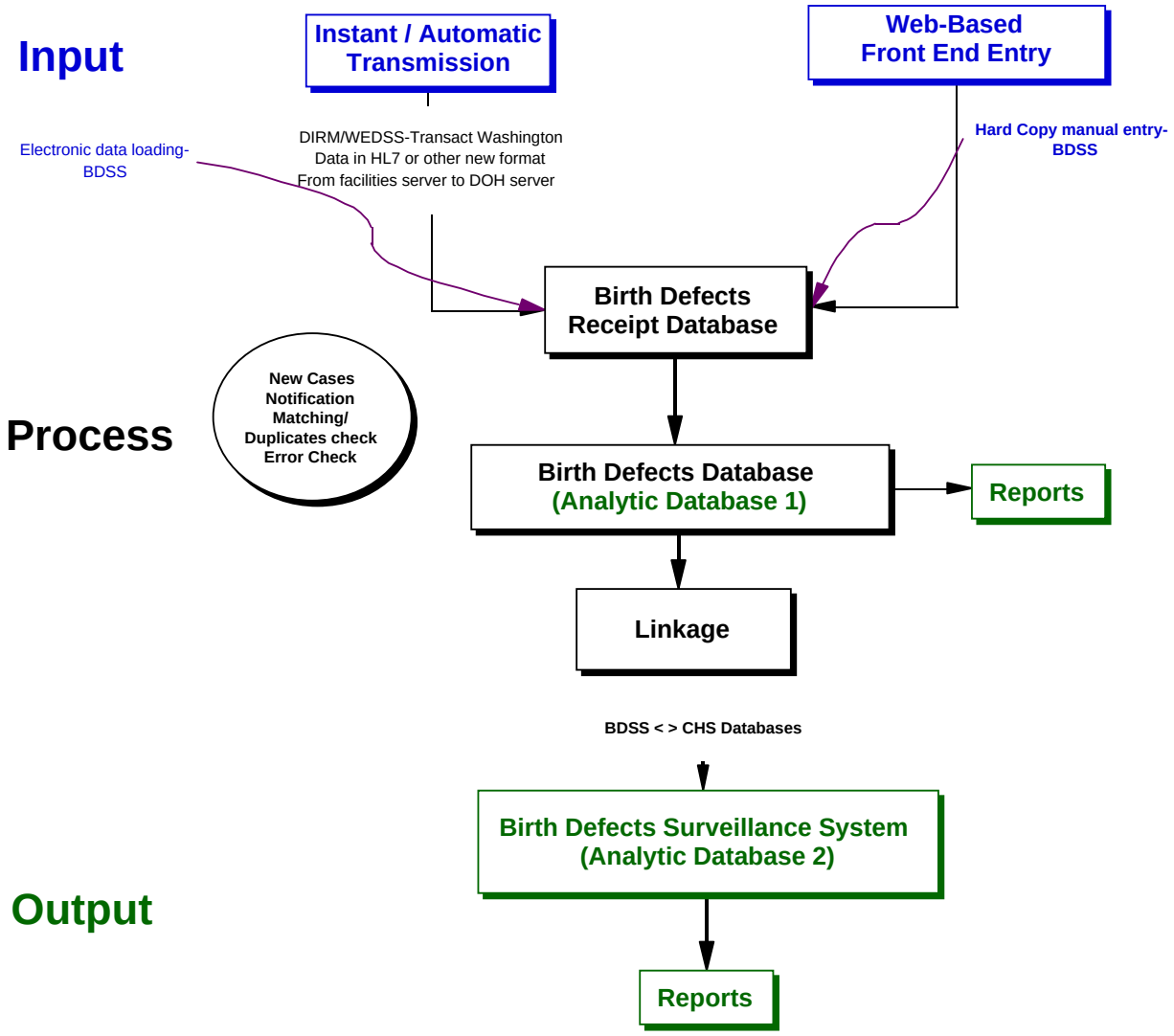
| | 2000 | | | 2001 | | | 2002 | | | 2003 | | | 2004 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] | Count[1] | Birth[2] | Rate[3] |
| **Anencephalus** | **6** | **79415** | **0.8** | **3** | **78021** | **0.4** | **5** | **77471** | **0.6** | **15** | **78858** | **1.9** | **8** | **80150** | **1.0** |
| **Spina bifida** | **5** | **79415** | **0.6** | **6** | **78021** | **0.8** | **10** | **77471** | **1.3** | **14** | **78858** | **1.8** | **11** | **80150** | **1.4** |
| **Cleft lip and or cleft palate** | **81** | **79415** | **10.2** | **88** | **78021** | **11.3** | **90** | **77471** | **11.6** | **76** | **78858** | **9.6** | **84** | **80150** | **10.5** |
| **Abdominal wall defects** | **33** | **79415** | **4.2** | **40** | **78021** | **5.1** | **36** | **77471** | **4.6** | **30** | **78858** | **3.8** | **23** | **80150** | **2.9** |
| **Down syndrome** | **45** | **79415** | **5.7** | **45** | **78021** | **5.8** | **49** | **77471** | **6.3** | **37** | **78858** | **4.7** | **51** | **80150** | **6.4** |

*Rates per 10,000 births for selected abnormalities 2000 - 2004

1 Number of birth defects reported
2 Number of total births included by reporting facilities
3 Number of cases per 10,000 births

## Appendix 4. Data Flow Chart of Future Birth Defects Reporting

### Washington State Birth Defects Surveillance System: The Future



## Appendix 5: List of partner facilities who reported to BDSS in 2003 and 2004

| Hospital | 2003 | 2004 |
|---|---|---|
| SWEDISH HOSPITAL MEDICAL CENTER | X | X |
| KLICKITAT VALLEY HOSPITAL | X | X |
| GROUP HEALTH COOPERATIVE CENTRAL HOSPITAL | X | X |
| GROUP HEALTH HOSPITAL | X | X |
| ST. JOHN MEDICAL CENTER, KESSLER CAMPUS | X | X |
| PROVIDENCE HOSPITAL | | X |
| ST. JOSEPH HOSPITAL & HEALTH CARE CENTER | X | X |
| COMMUNITY MEMORIAL HOSPITAL | X | X |
| DEACONESS MEDICAL CENTER | X | X |
| OLYMPIC MEMORIAL HOSPITAL | X | |
| KENNEWICK GENERAL HOSPITAL | X | X |
| WALLA WALLA GENERAL HOSPITAL | X | |
| PROSSER MEMORIAL HOSPITAL | X | X |
| ST. MARY COMMUNITY HOSPITAL | X | X |
| FORKS COMMUNITY HOSPITAL | X | X |
| WILLAPA HARBOR HOSPITAL | X | X |
| YAKIMA VALLEY MEMORIAL HOSPITAL | X | X |
| GRAYS HARBOR COMMUNITY HOSPITAL | X | X |
| SKAGIT VALLEY HOSPITAL | X | X |
| 076 | | X |
| SAMARITAN HOSPITAL | X | X |
| GENERAL HOSPITAL OF EVERETT | X | X |
| JEFFERSON GENERAL HOSPITAL | X | X |
| SKYLINE HOSPITAL | X | X |
| PROVIDENCE YAKIMA MEDICAL CENTER | X | X |
| VALLEY GENERAL HOSPITAL | X | |
| CASCADE VALLEY HOSPITAL | X | X |
| OTHELLO COMMUNITY HOSPITAL | X | X |
| HIGHLINE COMMUNITY HOSPITAL | X | X |
| UNIVERSITY OF WASHINGTON MEDICAL CENTER | X | X |
| NORTHWEST HOSPITAL | X | X |
| OVERLAKE HOSPITAL MEDICAL CENTER | X | X |
| ST. CLARE HOSPITAL | X | X |
| ISLAND HOSPITAL | X | X |
| LINCOLN HOSPITAL | X | |
| HOLY FAMILY HOSPITAL | X | X |
| KITTITAS VALLEY COMMUNITY HOSPITAL | X | X |
| HARRISON MEMORIAL HOSPITAL | X | X |
| ST. JOSEPH HOSPITAL | X | X |
| MASON GENERAL HOSPITAL | X | X |
| WHITMAN HOSPITAL AND MEDICAL CENTER | X | X |
| VALLEY MEDICAL CENTER | X | X |
| WHIDBEY GENERAL HOSPITAL | X | X |
| PROVIDENCE ST. PETER HOSPITAL | X | X |
| KADLEC HOSPITAL | X | X |
| SACRED HEART MEDICAL CENTER | X | X |

| | | |
|---|---|---|
| FERRY COUNTY MEMORIAL HOSPITAL | X | |
| CENTRAL WASHINGTON HOSPITAL | X | X |
| SOUTHWEST WASHINGTON MEDICAL CENTER, CENTER CAMPUS | X | X |
| PULLMAN MEMORIAL HOSPITAL | X | X |
| MARY BRIDGE CHILDREN'S HEALTH CENTER | X | X |
| VALLEY HOSPITAL AND MEDICAL CENTER | X | X |
| AUBURN REGIONAL MEDICAL CENTER | X | X |
| PROVIDENCE HOSPITAL - CENTRALIA | X | X |
| MOUNT CARMEL HOSPITAL | X | X |
| COLUMBIA CAPITAL MEDICAL CENTER | X | X |
| SUNNYSIDE COMMUNITY HOSPITAL | X | X |
| PROVIDENCE CENTRAL MEMORIAL | X | X |
| ST. FRANCIS COMMUNITY HOSPITAL | X | X |
| MADIGAN ARMY MEDICAL CENTER | X | X |